



Children and special needs is the theme for this issue of *ChildLinks*. The overwhelming message which comes through the various voices of policy makers, practitioners, parents and people with a disability is that in the important areas of early intervention and pre-school provision there are major difficulties and inadequacies for children with special needs.

In the article titled "Inclusive Education for Children with Special Educational Needs", Mary Meaney sets out the National Disability Authority perspective on the measures that have been taken since the enactment of the Special Educational Needs Act, 2004. She observes that one of the areas of intervention which has received least attention is that of pre-school provision.

experienced by parents of children with special needs. An initiative which aims to develop a model of good practice for the inclusion of disabled children in childcare settings, is set out in an article provided by the Disability Equality Specialist Support Agency,

In "Being 17" Caroline Casey gives a funny and moving account of growing up and discovering that she had a visual impairment. Her philosophy is best summed up in her parting line "...the only limitations we have are those we put on ourselves".

In the final article Fergus Finlay writes of his personal account as the parent of a child born with an intellectual disability. It sounds like every service she ever got had to be fought for. What impact will the Disability

Editorial

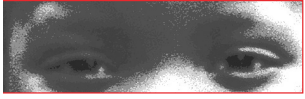
An example of an individual case of a Barnardos pre-school in working with a hearing impaired child is provided in "Helen's Voice". This article provides a really interesting account of how a child can be integrated into a pre-school and transfer to a primary school, with appropriate support and close collaboration by the pre-school service, the child's parents, the Department of Education, the Public Health Nurse and the primary school.

Parents' isolation, long waiting lists for assessment and children not receiving the early interventions that they need are reported in "Accessible Childcare for All". In addition, lack of access to information on grants, financial pressures, the costs of transport, lack of access to counselling and to respite facilities were cited as barriers

Act make which gives people with disabilities the right to an assessment, enquiry, appeal, etc but not a right to services?

How different will it be for children born with a disability in 2006, who have the benefit of the Disability Act and the Disability Strategy? The National Disability Authority and the Centre for Early Childhood Development and Education need to exercise leadership to ensure major development and expansion of early years care and education for children with special needs.

Anne Conroy Editor



INCLUSIVE EDUCATION

for Children with Special Education Needs



MARY MEANEY, Senior Policy and Public Affairs Advisor, National Disability Authority

INTRODUCTION

The education of children with special educational needs has become a major focus over the past decade. Scarcely a week now passes without some item in the media highlighting an aspect of special education. The education system has, over the past eight years in particular, put in place a range of supports to assist children with special educational needs to progress through their schooling. The majority of these children attend mainstream schools while special schools provide education services for children with more complex needs. The trend towards inclusion has become enshrined in legislation in the Education for Persons with Special Educational Needs Act, 2004. Since last July all schools are legally required to provide inclusive education, where this is in the best interests of the child concerned and where it is consistent with the effective provision of education for other children. The 2004 Act defines special educational needs as “a restriction in the capacity of the person to participate in and benefit from education on account of an enduring physical, sensory, mental health or learning disability, or any other condition which results in a person learning differently from a person without that condition”. In order to benefit from additional supports a child’s condition must fit within this definition.



LEGISLATION AND EDUCATION

The Education for Persons with Special Educational Needs Act was passed in 2004. It recognises that persons with special educational needs have the same right to an education as their peers who do not have such needs. It sets out the procedures for identifying/assessing special educational needs and details how these needs must be addressed. The actual provisions of the legislation will come into effect over a period of several years. Some are in force already, among them the requirement for inclusion. This provision means that in future, fewer children will attend special schools and most children with special educational needs will attend 'mainstream' schools.

Other significant developments include the establishment of the National Council for Special Education (NCSE) which has its headquarters in Trim, Co. Meath. The Council describes its role as working to deliver a better special education service. It has a power to designate a school for a child. In making a designation the Council must consider the parents' wishes and the capacity of the school to meet the child's needs.

Another important feature of the Act is that it provides for a comprehensive appeals system. Parents may bring appeals on a range of issues, for example a refusal to carry out an assessment, a failure to implement any part of an education plan, a refusal to review the plan, a difference over any statement or description in the plan where the parents believe it is inaccurate. The appeals process will be administered by the Special Education Appeals Board. At present there is no timeframe available to indicate when the Board will commence its work.

The school, Health Service Executive or the Council may arrange for the assessment of a child. The Act provides that the assessments must commence promptly (within one month) and must be completed without delay. Parents may request an assessment in respect of their child. There is a duty on professionals in schools or health services to consult with parents and arrange an assessment where teachers / psychologists / health workers etc believe that the child may have special educational needs.

The 'Education Plan' is the central document by which special educational needs are outlined and relevant supports and goals for the child are recorded. The plan must be prepared by a group of persons which includes the parents of the child and may include the child (the parents however may decline to participate). The education plan must be reviewed at least once a year and parents must be informed of the outcome of the review. The NDA publication "International Experience in the Provision of Individual Education Plans for Children with Disabilities" is available on www.nda.ie or in hard copy on request.

The Disability Act, 2005 provides for assessment of children (and adults) and sets out eligibility criteria for entitlement to services under that Act. A child with a disability may be assessed under this or the EPSSEN Act. Where special educational needs are identified in an assessment under the Disability Act, these needs must be

referred to the relevant school (if the child is a student) or to the Council. The 'education plan' will be informed by the range of needs and will outline how these will be addressed. Similarly where an assessment under EPSSEN identifies health needs, these needs must be dealt with by the Health Services Executive in a 'service statement'. The two Acts provide the framework to deliver specialist services to children with disabilities. The same standards will apply to assessments carried out under either Act.

NEW STATE ORGANISATIONS

There are a number of recently established organisations working in the area of special education. The National Council for Special Education (NCSE) was set up to improve the education experience for children (and to a lesser extent adults) with special educational needs. The Special Educational Needs Organisers, of whom there are 80) are assigned to various locations throughout the country. Information on the NCSE can be found on www.ncse.ie.

The Special Education Support Service is another new service. It focuses on providing information to schools and staffs on effective responses to special educational needs. The website www.sess.ie has an extensive range of information including many official documents.

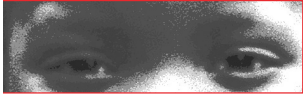
The Special Education Appeals Board is to be set up to administer an appeals system which will give parents an opportunity to bring disputes to an independent body for resolution. Parents of minors with special educational needs may bring complaints to the Minister or take court action. In either of these situations the matters may be referred to mediation.

CATEGORIES OF SPECIAL EDUCATIONAL NEEDS

There are 14 categories recognised by the National Council for Special Education (NCSE):

- Physical disability
- Hearing impairment
- Visual impairment
- Emotional disturbance
- Severe emotional disturbance
- Borderline general learning disability
- Mild general learning disability
- Moderate general learning disability
- Severe/ profound general learning disability
- Autism/ autistic spectrum disorders
- Specific learning difficulty
- Assessed syndrome
- Speech and language disorder
- Multiple disabilities

Each category of need is supported by additional resources. The details of the resources and the amount of support are available from the NCSE or the local Special Educational Needs Organiser (SENO).



WHAT IS AVAILABLE IN PRACTICE FOR CHILDREN WITH SPECIAL EDUCATIONAL NEEDS AT PRESENT?

Early intervention – pre-school placements

Children with special educational needs benefit from intervention at as early a stage in their development as possible. Unfortunately finding an early intervention and/or a pre-school service is often a major difficulty. Getting an assessment done can be a very slow process and every day the child has to wait can intensify the child's special educational needs. There are long waiting lists for assessments and where these have been completed the children then often have to join another long waiting list to access services such as speech and language and other forms of therapy. The whole area of assessment and early intervention services remains underdeveloped and is in need of major expansion.

Supports for children with special educational needs in the school system

In contrast with pre-school services primary school services are well developed. The range of supports for children with special educational needs includes additional teaching, special needs assistance, transport, IT resources, adapted furniture and general adaptations to school premises to make schools accessible.

Additional teaching on a one-to-one basis or in small groups is the most common intervention provided. Some children will be entitled to a Special Needs Assistant, who will look after the care needs of the child while he/she is at school. Getting from home to school and back again is an essential journey and a child with special educational needs may be provided with free transport. An escort service may be available in specific circumstances. A child who uses a wheelchair may well benefit from a 'rise and fall' table / desk in school and this may be provided. Where ramps and or lifts are needed these can be provided. It is essential to let the school know about these requirements as long before the child begins to attend the school as possible because some school modifications must go through the planning process which can be slow and complex. Computers and IT programmes can be of benefit to some children with special educational needs and dedicated computers will be available for pupils for use at school subject to eligibility criteria.

In general similar supports are also available at second level. However the system there is not as yet as developed as the primary sector. However this is likely to change as children transfer from first to second level education.

MAKING INCLUSION WORK

In order to make inclusion work there are steps schools, teachers and parents should take. Schools should make sure that the enrolment policy and enrolment practices are genuinely inclusive. In addition school buildings and grounds should be accessible and, where necessary, the built environment should be upgraded or adapted to achieve full physical accessibility.

Teachers should ensure that they use a range of appropriate teaching methods and adapt the curriculum when necessary for children with special educational needs. They should also foster a positive social environment for all students.

Parents can assist the school by making contact with the school well in advance of the time the child will actually attend and they should ensure that relevant reports are provided to schools. When this happens schools have time to make applications for the various supports available for the child and if necessary to adapt the building where appropriate.

Good communication between the school and home will promote a positive educational experience for the child. Depending on the particular circumstances the parents might wish to seek the advice of the school and in addition the advice of the SENO about certain matters. Every school has a designated SENO and the contact list is posted on www.ncse.ie.

SPECIAL SCHOOLS

Special schools are an important aspect of provision for children with special educational needs who require intensive support which cannot be provided in the mainstream school. There are about 120 'special schools' in the country and, in addition many 'special classes' operating in ordinary schools. These schools have great experience in responding to students' needs. The possibility of extending their role into a resource centre for mainstream schools is one that should be considered. A list of all special schools is available on www.education.ie.

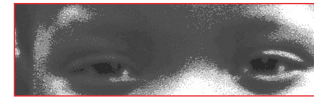
SCHOOL COMPLETION PATTERNS

One of the positive features of the recent legislation is that it provides for supports for children as they move from pre-school to primary and again from primary to post primary schools. This should assist in keeping children with special educational needs in the education system so that they complete their second level education and move to further education afterwards. Unfortunately to date the school completion patterns among students with disabilities show trends of early school leaving and few qualifications.

Research by AHEAD has identified that only 17% of second level schools in 1998 were considered by their principals to be fully accessible. This may well be a factor in early school leaving among students with a disability.

The NDA has commissioned research from the Children's Research Centre, TCD to identify the factors behind this phenomenon of early school leaving, and the NCSE is on the advisory body overseeing the research. The report should be available by the end of 2006.

The Census of 2002 showed that at age 15 – which is below the minimum school-leaving age of 16 – over 20% of young people with physical disabilities, 13% of young people with hearing or vision impairments, and 16% of young people with learning or intellectual



disabilities had already left school. This compares with 6% of non-disabled students. These young people with disabilities generally leave school without acquiring a Junior Certificate. So when we look at the qualifications of disabled young adults aged 25-34, over 20% have no qualifications (i.e. no Junior Cert, Leaving or higher qualifications) compared to 4% of non-disabled peers.

For students with disabilities, early school leaving and poor qualifications in turn are strong predictors of a lifetime without work.

The table below gives the link between education levels and employment rates for disabled and non disabled men aged 25-34. Young adults with disabilities experience much steeper rises in employment rates the higher their education qualifications, and conversely the penalty for poorer qualifications is much greater in the case of young adults with disabilities.

Proportion of men aged 25-34 in work, by education and disability (Census 2002)

Highest education	Disabled	Not Disabled
Primary	21.8%	64%
Junior Cert	37%	85%
Leaving Cert	51.2%	91.9%
Other 3rd level	63.4%	94.1%
Degree or higher	71.2%	94%

Proceeding to Leaving Cert raises subsequent employment rates of disabled students by 14 percentage points compared to completion at Junior Cert, and by 30 percentage points compared with school completion without qualifications.

The National Disability Authority therefore identifies support for school completion and career guidance as key issues for the subsequent life chances of disabled students.

SCHOOLS AND EDUCATING STUDENTS ABOUT THE NEEDS OF PERSONS WITH DISABILITIES

One of the barriers which people with disability face is the attitudes of others. This barrier is likely to be reduced and minimised by an appropriate education programme. One of the new duties for a school (which has yet to actually to come into effect) is to educate students about the needs of persons with disabilities (Section 14, Education for Persons with Special Educational Needs Act, 2004). This approach has the potential to promote greater understanding of the needs of persons with disabilities and to enhance their inclusion and participation in society.

A FINAL WORD

There have been many improvements to the education provision for children with special educational needs of school-going age over the past ten years. Others are planned during the course of the implementation of the provisions of the Education for Persons with Special Educational Needs Act, 2004. Unfortunately the level of services for children in the pre-school years remains extremely inadequate as does education provision for young adults with disabilities. These two areas, in particular, require urgent development so that the children with special needs will have an opportunity to leave school with the skills necessary to participate fully in society and fulfil their maximum potential.

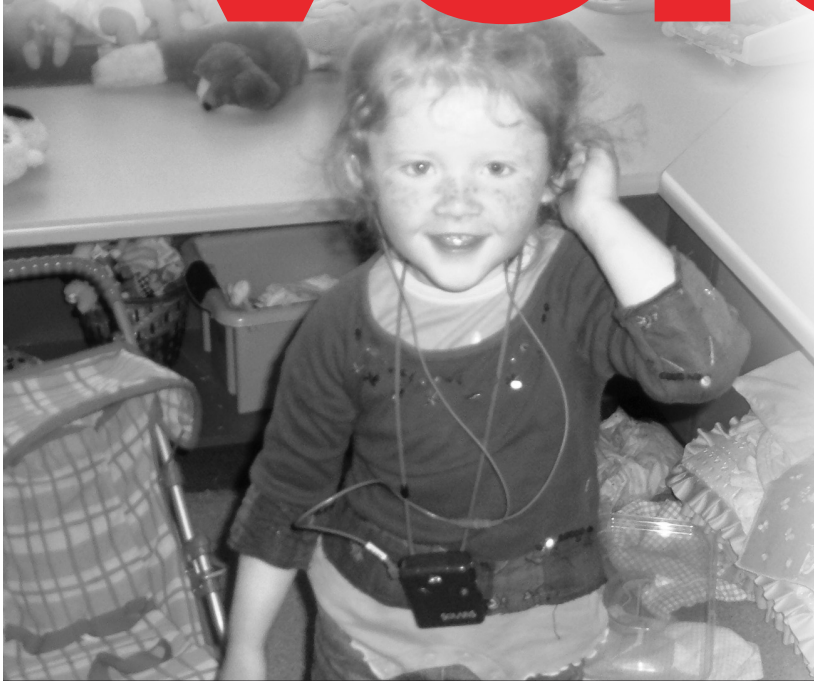
FURTHER INFORMATION

Parents will be interested to note that the NCSE has a statutory obligation to provide information to parents of children with special educational needs in relation to the entitlements of their children and their own entitlements under the EPSEN Act.

The National Disability Authority (NDA) has produced an information booklet on the Act "Education for Persons with Special Educational Needs Act". This is available on www.nda.ie.



HELEN'S Voice



The experience
of one Barnardos
pre-school of
working with a
hearing impaired
child

ESTHER PUGH, Project Leader, Labre Park Children's Service

INTRODUCTION

This article has been written to share the experience of our pre-school of working with a hearing impaired child from first diagnosis to progression to school. It will examine how Helen, who has been diagnosed “moderately deaf”, started to learn to speak as a result of a planned intervention in the pre-school. It will look at her deafness in the context of her culture and community and the obstacles which she has had to overcome in the past two years. It will illustrate how the pre-school staff have learned to work with a hearing impaired child and use the available resources to develop her language. It examines the challenges going forward and the supports that have been put in place for her as she goes through the transition to main stream education.

Labre Park Children's Service is located in a Traveller Housing Scheme in Dublin 10. Barnardos has been working with young children in the area since 1987. Up until 1996, Barnardos provided a mobile education service or Play Bus to Traveller children in Clondalkin and Ballyfermot. Barnardos has been operating out

of a custom built centre in Labre Park since 1997 and aims to provide quality early years, after school and family support services, which meet needs and rights of the families in this community for children aged 3–8 years. Currently the pre-school operates five mornings a week for up to 15 children.



Within Labre Park, approximately 60% of the population in the community are accommodated in Traveller Specific Housing. The remaining families live in mobile homes in the housing scheme on a permanent basis. There are 22 families living in Caravans or Mobile Homes, some of whom are living in appalling conditions. Nomadicity, although still part of the memory of the families and part of the cultural identity of the community, is now rare. There are 151 children in the community under the age of 18 years.

Families living in the housing scheme face a high level of discrimination and marginalisation in their daily lives. Within the community itself, difference is viewed with suspicion and is often hidden or information relating to it is kept confidential within the immediate family.

Like many of the Barnardos early years services, the morning pre-school session is an active and noisy place to be, unless you are a child who cannot hear.

WHAT IS SOUND?

According to the International Deaf Children's Society, sound is an invisible vibration. It travels in waves, spreading outwards from the source of the sound. Sounds are different both in loudness and pitch, often known as frequency.

Loudness is measured in decibels (dB). Pitch or frequency is measured in Hertz (Hz).

All sounds are made up of different frequencies. We can describe this as the pitch of the sound. The frequency of sound affects the pitch this it is heard at. The sound that a whistle makes when it is blown is an example of a high frequency pitch whereas the noise made when banging on a drum is an example of a low frequency pitch.

Speech consists of sounds of mixed frequencies. Consonants are generally higher in frequency than vowels. Some children's hearing impairment is the same across all the frequencies. For other children, their deafness occurs at different levels, depending on the frequency.

LEVELS OF DEAFNESS

The level of deafness is defined according to the quietest sound you can hear, measured in decibels.

There are four categories used to indicate the level of an individual's hearing loss:

Mild deafness	20 – 40 dB
Moderate deafness	41 – 70 dB
Severe deafness	71 – 95 dB
Profound deafness	95+ dB

The early use of hearing aids, before 6 months of life is recommended and has better outcome in terms of speech and language development for children who have moderate to severe hearing loss. People who have moderate deafness have difficulty following speech without a hearing aid, and find the quietest sound they can hear are 41–70 decibels.

CASE STUDY: Helen's Story

Helen was referred to the service by her mother who requested a place in the service in July 2004. She is the second eldest of a family of four children and started in pre-school on her third birthday in September 2004. She lives with her mother, Kathleen and father, Stephen (who has a severe hearing impairment) and three siblings in a two room mobile home. As the only daughter she is extremely protected within the context of her culture.

Following up on the referral, first contact with Helen took place on a home visit in August 2004. It was observed that Helen had very poor language development and was easily frustrated at the time of the visit. Her mother, Kathleen, told her key worker that she was worried and thought that there was something "seriously wrong" with her child. Permission was sought from Kathleen to contact the Public Health Nurse in relation to her development checks. The Public Health Nurse had recorded that at 14 months there were some concerns about Helen's hearing but that she had failed to show up at subsequent appointments since that time.

Helen started in the pre-school the following week and was an extremely withdrawn child who had a high level of dependency on her older sibling. He had also started in the pre-school at the same time. He often acted as a translator for her as she had no recognisable words. When she spoke she could not be understood by the staff or by her peers. She had some limited understanding of what was being said to her, but it was observed that this only occurred if she was facing the person talking to her. It was suspected that Helen had a serious problem with her hearing which was affecting her speech.

In her first week in pre-school she was referred for a hearing test and for speech and language assessment. Recurrent ear, nose and throat infections delayed the final diagnosis of the extent of her hearing impairment until March 2005. From September to February Barnardos, in conjunction with the Public Health Nurse, advocated on Helen's behalf and secured early specialist appointments in Our Lady's Hospital for Sick Children and an operation date to address her medical problems. Her case was referred to the National Purchase Fund by Barnardos in February 2005 under which she received a tonsillectomy, had her adenoids removed and had grommets fitted.

Once her medical problems had been treated, her hearing deficiency could be accurately assessed. Helen was found to have moderate hearing impairment. This means that she cannot hear sounds within the speech range which occurs at 41-70 dB. Although called moderate, it is in fact a significant hearing loss especially as it had been diagnosed at such a late stage. It is thought to be extremely likely that her condition is genetic and has been present since birth. Helen would now need to develop a high level of concentration to build spoken language through the consistent use of hearing aids. Helen was fitted with her first hearing aids in April 2005.

In those first early months in pre-school, Helen became upset and frustrated easily. She did not like to be approached or consoled. She played alone and was reluctant to join in any peer led or adult



facilitated group activities or games. She was isolated by her peers and was self isolating. Always extremely wary of change or new experiences, she was a constant onlooker, watching everything from a distance. On a good day she would play alone in her own world, shadowed by her key worker, looking for opportunities to engage with her at any level. On a bad day, she would sit and scream at anyone who approached her:

Her reliance on her older sibling continued for the rest of the year until he left to attend school in 2005. However, by mid year she began to accept and enjoy adult company and interacted positively with staff. She took her lead from either her mother Kathleen or her key worker. Helen was not successful in forming any friendships with peers with the exception of her brother, and opted to play alone or with her key worker.

Observing her from a distance today as she is in her last term before starting school, you might notice that when she is playing with her friends her eyes focus on their lips. She is very protective of her best friend and will look out for her in play, ensuring that no other children take her toys. Moving in closer, you will hear her speak in very short sentences and notice that when she does not know the name of an object or word, she will point to what she wants to make herself understood. You might observe that she still gets frustrated when she cannot make herself understood. When this happens she will revert to playing alone, but with the support of her key worker will rejoin the play as she is supported to find the language she needs to express her emotions and explain her needs. She might show you her hearing aids. She is very proud of them and calls them her "ear rings". Helen has come a long way in the past year; she has made friends, started to talk and can listen and join in at story time. However her linguistic development is still that of a two and a half year old which represents a delay of two years. Despite this, Helen is school ready and will be starting in main stream education in September 2005 with the support of a Personal FM Radio system which she has been using in pre-school since January 2006.

Although she has a delay in her language development, Helen, like the majority of deaf children doesn't have a speech problem. There is nothing wrong with her ability to move her mouth, tongue, lips or vocal cords. What has interfered with her learning to talk is the quality of what she heard up until the time she got her first hearing aids.

DIAGNOSIS AND SUPPORTS

The final diagnosis of Helen's hearing impairment at three years and seven months provided links into the services and resources which she urgently needed. It provided her family and the staff in the pre-school service with information, advice and support. The greatest support to both Helen and the pre-school staff team was that of the Department of Education and Science Visiting Teacher Service for the Hearing Impaired (VTHI).

DEPARTMENT OF EDUCATION AND SCIENCE VISITING TEACHER SERVICE FOR THE HEARING IMPAIRED (VTHI).

The visiting teacher service is available to all deaf and hard of hearing children from the time of diagnosis through to education completion.

Each visiting teacher is allocated a caseload of pupils. The nature and frequency of visits will depend on a range of factors including the age of the child, severity of hearing loss, educational placement and individual learning needs.

The visiting teacher service:

- Provides guidance and support for parents in the home
- Supports parents in their growing awareness of the effects of deafness on the child, the parents and the extended family
- Informs parent of the implications of deafness for the acquisition of spoken language and Irish Sign Language (ISL)
- Informs parent of the implications of deafness for the acquisition of spoken language and Irish Sign Language (ISL)
- Informs parents of communication methods and supporting them in their choices
- Demonstrates strategies for developing language and communication skills for parents and family
- Liaises with audiology services, assisting parents in the management of hearing aids and equipment, and interpreting audiological information
- Monitors language development and communications skills
- Provides comprehensive information and advice on the range of pre-school and school placements.

Kathleen, Helen's mother, and pre-school staff found the VTHI service to be a great support for a number of reasons. Kathleen and her husband Stephen report that they were able to come to terms with the diagnosis because of the approach adopted and the support provided by the Visiting Teacher Service. They took on the responsibility for all of her audiology appointments and for following through on additional appointments. From the beginning, they were open and honest about her hearing impairment and encouraged other community members to become comfortable with her use of hearing aids. They explained to community members who showed an interest how to talk to Helen by getting down to her level and keeping within the radius of the aids.

The VTHI focused on the positive aspects of Helen's future development, clearly informing them of their choices in relation to her future education. She advised that the maximum effort should be put into developing Helen's spoken language. She explained that with the introduction of the hearing aids she would be capable of developing language. Developing language was also a necessity for Helen as reliance on Irish Sign Language (ISL) would not be an option for Helen within her community. In order for Helen to fit into the community she had to learn to talk. Sign language is the natural language for deaf children only when it is the natural language of the home. Sign language uses movements and vision to convey meaning and is organised in a way which is fundamentally different to spoken language. It is difficult for hearing people, whose language developed through listening, to fully master sign language unless they were exposed to it as a young child. The parents and family of a deaf child are not normally fluent sign users, and are unlikely to



become so during the early years that are vital to language acquisition. Although Helen's father is also deaf, he relies on speech to communicate.

Helen's parents were clear from the outset that they wanted her to remain in the pre-school and to attend main stream education in the local school when she was school ready. They had built a good relationship with the school through their older child. Barnardos, through the after school programme in the service also have a positive relationship with the school. The VTHI fully supported this choice and with the assistance of the Visiting Teacher for Travellers (VTT) arranged for a four way meeting between Helen's parents, Barnardos, VTT and VTHI at an early stage to ensure that Helen could be enrolled in the school for 2006 and the appropriate equipment and supports put in place.

She assisted both parents and Barnardos staff on the practical issues of maintaining the hearing aids, supplying sufficient batteries, monitoring Helen's physical growth to ensure that the hearing aids fitted properly and were comfortable. She also attended the service regularly, observing Helen's progress, and supported staff who were made aware of the extent of Helen's hearing impairment. On these visits she took time to meet with staff and parents giving ongoing support and feedback. She was and continues to be accessible and available to the family and the Barnardos staff and directs staff as to how best to work with Helen.

WORKING WITH HELEN

As a result of Helen's lack of language, it was not deemed appropriate that she should attend speech and language therapy until she had built a repertoire of words and she completed a further assessment at age 5. The first and most important piece of work was to introduce Helen to the world of spoken language. Helen's parents and Barnardos worked in partnership, sharing information, meeting on a regular basis (often daily) to ensure that everyone was fully aware of her needs and any new developments.

The process of developing Helen's speech was carried out in two distinct stages. From September 2004 until July 2005 staff worked on building her vocabulary and integrating her into the preschool setting. From September 2005 to the present staff worked on the development of language through listening and talking known as the Natural Aural Approach. Work with Helen was carried out on both individual and group levels. Helen's Key Worker took the lead in this, however the pre-school team worked together to maximise her opportunities for acquiring language. As part of the anti-bias curriculum, the other pre-school children were also supported to understand and to become comfortable with difference. This was done through the use of books, pictures and a doll that was fitted with hearing aids.

WEARING THE HEARING AIDS

It took a number of weeks to build up Helen's capacity to wear the new hearing aids. Initially Helen liked her hearing aids and would wear them both at home and in the pre-school. However as the novelty wore off and Helen got tired concentrating she often removed her hearing aids and went back to relying on lip reading

or tuning out. Both her parents and the staff worked with her to encourage her to wear the hearing aids. For two months she wore the hearing aids only in the pre-school as an interim measure. Slowly her capacity to wear the hearing aids was rebuilt. However, this still varies and is a constant challenge for Helen and her family. She is allowed to take her hearing aids out at home and have a rest, but is encouraged to put them back in later in the day.

DEVELOPING LISTENING SKILLS

Staff concentrated on developing Helen's listening skills. When talking to her, sentences were kept short but grammatically correct. This was enhanced by showing her items and telling her what they were, always using good intonation, e.g. "Look at this Helen, this is a telephone, will we answer it?" Some of the suggestions the VTHI made were to keep a diary of her hearing, use flash cards and books to develop her vocabulary, do one to one work in a quiet area and to teach her to listen for her name. Helen needed to learn to rely less on body language, gestures, eye signals, lip reading and touch. Helen's mother was very interested in this and met with staff and the VTHI on a regular basis and carried the work into the home.

DISCOURAGING LIP READING

Helen was a self taught lip reader, and it was imperative that she learned to move away from this and to listen for language. Her lip reading ability was not accurate and she was guessing most of the words spoken to her, often guessing wrong. This caused her to become both frustrated and angry. The VTHI explained to us that once she had developed some knowledge about sound and language, lip reading can be a useful extra aid when things are difficult, for example, when there is a lot of background noise. This is when the hearing population use lip reading. The use of the hearing aid ensured that Helen could pick up all sounds spoken at a normal pitch within a one metre radius.

A hearing child talks because they hear people talk. A child with a hearing impairment will talk if she is given enough experience of sounds, but talking happens much later for a hearing impaired child.

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WORKING ON INTONATION AND RHYTHM

It was also important to ensure that Helen developed socially, emotionally and educationally despite her hearing impairment. Because of this, early intervention is essential. All of the significant people in the child's life must be prepared and willing to work with the child. This includes parents, siblings, relatives, friends and pre-school.

It means that the child must be encouraged to listen to normal speech, to watch and to be aware. Speech spoken at normal speed



is full of rhythm and intonation. We know that it is the rhythm and intonation that children find easiest to hear and learn. So, groups of words, e.g. “look at that” are easier to hear than single words e.g. “look”. Long words e.g. “elephant” are easier to hear than short words e.g. “cat”. This level of interaction must be carried out every day by significant adults and not just when you feel like doing so. Helen has a large extended family who have the time to talk to her, and her mother keeps up a continuous dialogue with her. A deaf baby who gets hearing aids early in life is at a distinct advantage over a child like Helen who was not diagnosed or fitted with hearing aids until she was 3 years and 7 months.

SETBACKS

As Helen’s vocabulary built she learned to name objects and how to listen for cues. However the late diagnosis of her impairment had a cumulative effect on her language development and on her ability to tolerate the hearing aids which she finds difficult to wear for long periods of time. In September 2005, which was the beginning of her second year in pre-school she continued to be isolated from her peers having regressed in language development over the summer break when she refused to wear her hearing aids at home.

THE NATURAL AURAL APPROACH

The VTHI introduced both Helen’s family and the Barnardos Staff to a new approach of working with Helen in September 2005. This followed on from the ground work of the previous year. This approach is called the Natural Aural Approach. Deaf Education through Listening and Talking (DELTA) advocate using the Natural Aural Approach for all deaf children regardless of the level of impairment. Not all children born with a severe or profound hearing loss will develop normal speech, but the great majority who are brought up using the natural aural approach will acquire fluent speech which can be easily understood by strangers. Learning to talk with even a little sound is much easier if the child gets plenty of opportunity to listen to others and to practise talking. The Natural Aural Approach has been developed by practitioners, teachers and parents of deaf children. The methodology is based on current research and developments in three disciplines.

AUDIOLOGY – ensuring that each child’s auditory potential is maximised through all waking hours.

ACOUSTIC PHONETICS – providing an experience of naturally spoken language rich in normal acoustic information needed for the auditory acquisition of language.

FIRST LANGUAGE ACQUISITION – providing the deaf child with similar language experiences to those which have been shown to aid child language acquisition in hearing children throughout the world.

The key component of this approach was to maximise Helen’s auditory potential. Hand in hand with this was the need to address the impact that Helen’s hearing loss had on her social development, most noticeable in her isolation from her peers. She had not developed the social skills that other children acquire independently by virtue of having normal hearing.

Helen could hear speech through her hearing aids within a radius of one metre. However, hearing aids also amplify background noise. Staff knew that they would have to be physically close to her if Helen was to hear them talking. Staff planned daily and positioned themselves within the play environment to best maximise Helen’s opportunity to hear them. Individual work was also carried out on a daily basis. Helen continued to learn and used what language she had in her interactions with other children. However, in their play, children moved naturally around the room and as a result in and out of Helen’s hearing range. This gave confusing non verbal messages to both Helen and the other children who misinterpreted this as “I don’t want to play with you”.

Following a meeting in September 2005 between Kathleen, the VTHI and Barnardos staff it was agreed to introduce a Personal FM Radio System for Helen in the pre-school. This was done to enhance Helen’s speech as part of the Natural Aural Approach and to start on the process of preparing her for school where the system would be in place.

The FM Radio System comes in two parts: a receiver which is worn by the child and connected to hearing aids and a transmitter worn by the person speaking to the child.

OUTCOME

Since the introduction of the FM Radio System into the pre-school, Helen’s language has developed at a steady pace. As her peers have the opportunity to wear the transmitter in play, she has developed some of the social skills which are necessary to form friendships and become integrated into the group. Her speech is more distinct and her pronunciation and diction are clearer. She has begun the process of making herself understood and can express some of her needs. The existing language delay which is still significant will reduce



over time. At her most recent assessment by the VTHI, it was confirmed that she is progressing at a steady pace and doing well given her use of hearing aids and the FM Radio System.

The Natural Aural Approach is a method which suits and empowers her parents to carry out the same programme in the home. Kathleen has told us that she is more confident in her ability to work with Helen on her language development.

GOING FORWARD

It is anticipated that Helen's language will continue to develop through the use of the hearing aids and FM Radio system. Helen still experiences difficulty in wearing her hearing aids, and likes to take them out and rest after pre-school. As we approach the end of the pre-school year, she will need extra support and encouragement over the summer months to wear her hearing aids. These supports have been planned and include a schedule of home visits, including Helen on a longer summer programme and doing individual work with her over the summer period. Kathleen is extremely diligent about managing her audiology appointments and

feeding back to the service. With the support of Barnardos and the VTHI, she has grown in confidence and is Helen's best asset and advocate. Kathleen has said that she would like to share Helen's story with other parents and teachers to raise awareness of her ability. This she says is especially important within the Traveller community.

Helen has been enrolled into the local national school for September 2006. She has secured a special needs assistant through the Department of Education and her class teacher for next year has met with both Helen's parents and Barnardos. The teacher is familiar with and has experience of using the FM Radio System as she has a child in her class this year with a hearing impairment. This has given Helen's parents confidence that they have made the right choices for Helen. Kathleen and Stephen arranged to visit the school last month. They met Helen's teacher to discuss Helen's needs and took the opportunity to observe her working with the class.

Helen will continue to be supported by Barnardos until the age of 8 years and will transfer into our after school programme in September.

References

- Classification of Deafness – M Hickey www.teachnet.ie
Deaf Education Through Listening and Talking (DELTA) www.deafeducation.org.uk
Fraser, B. (1996) *Supporting Children with Hearing Impairment in Mainstream Schools*. London: Franklin Watts.
Moeller, Mary Pat (2000) Early Intervention and Language Development in Children who are Deaf and Hard of Hearing, *Pediatrics* Vol. 106 No 3.
SERC (1993) *Report of Special Education Review Committee*, Dublin: Government Publications, Department of Education and Science.



Monica Cassidy speaking at the launch of *Accessible Childcare for All*

Accessible Childcare FOR ALL

The Dublin City Childcare Focus Group is a voluntary group that was formed in 2001 under the auspices of the Dublin Community Forum. It is a group of community and private childcare providers and parents accessing childcare services. The aim of the focus group is to encourage two-way communication between childcare providers and parents through our representation on the Dublin City Childcare Committee and the Dublin City Development Board through our representation on the Community Forum.

Our terms of reference include promotion of quality in regard to childcare issues, which led to the publication of our document *Accessible Childcare for All* in 2004. The primary aim of the research project was to identify and promote solutions designed to ensure

equality of access and opportunity in terms of childcare provision for children with learning, sensory, physical and emotional additional needs and for children whose parents have a disability. This research was funded by the National Disability Authority and published by



the Dublin City Childcare Committee. Although the research concentrated on the area of North West Dublin, (including Finglas, Ballymun, Whitehall and parts of Santry and Glasnevin) its findings and recommendations are nevertheless relevant for all policy makers and childcare providers.

Many different groups provided information for this research from both private and community providers to parents and special needs services. While the research highlights providers' commitment to supporting children and parents with additional needs is evident: "Sixty-eight percent of providers stated that they had never turned away a child because of their additional needs." Some parents felt that this had not always been the case as the places being offered were not suitable for their child's needs. In particular this was the case where the child's additional needs were more pronounced.

Providers identified funding for training in special needs as a huge block to supporting children needing additional supports. The 1999 OECD Report states: "Training is the most important vehicle for creating a workforce with values, attitudes and specific skills compatible with the goals of inclusion." Providers also conceded that not only did lack of trained specialist staff hamper their commitment but the lack of knowledge around dedicated grants to improve or renovate their settings.

Many parents reported a sense of feeling isolated and this was exacerbated by the long waiting lists parents experienced while waiting for a diagnosis. Parents who took part in the research raised the issue of lack of access to information about grants for their child's needs. The fact that resources are scarce results in children not receiving the early interventions they need. Access to counselling and respite services were considered by parents as being essential to supporting them in their parenting role. For parents with additional needs access and communication difficulties identified. For parents with additional needs and parents of children with additional needs financial pressures and cost of transport was a huge issue. Financial difficulties increase when parents identify the lack of information around grants to support them.

The findings served to highlight the scarcity of researching the area of children with special needs. Government policy and commitment to ensuring equality of access for all children, but specifically those with additional needs, is guaranteed under the 1998 Education Act and the Equal Status Act of 2000. Mainstreaming children with additional needs was identified as a priority in the document *A Strategy for Equality* in 1996 by the Commission on the Status of People with Disabilities, but to date there has been a failure in addressing the specific requirements needed for these children and parents in accessing pre-school services.

In their document *On Target*, The Centre for Early Childhood Development and Education (CECDE) recognised the uncoordinated

and fragmented pre-school provision that is available to children and parents with additional needs. The lack of forward planning and commitment to supporting children and families with disabilities was addressed by DESSA¹, The Disability Equality Specialist Support Agency, at their conference, Lets All Play, where stakeholders came together to look at ways to integrate children with disabilities into mainstream private and community services. As part of their brief DESSA will offer specialised training in developing inclusive play policies for their practice. It is envisaged that the Dublin City Childcare Focus Group will work closely with DESSA to continue to develop models of good practice so that the needs and rights of children with disabilities will be mainstreamed into any future policy developments. The Dublin City Childcare Focus Group recognises that mainstreaming services and developing good working links with both staff working on the ground, parents and statutory providers is essential if the needs of children and parents with additional needs are to be met.

Arising from the research undertaken by Dublin City Childcare Focus Group a decision was taken to devise a protocol for inclusion for all early years settings. It is envisaged that the protocol will be introduced to all childcare providers in Dublin City by the end of 2006. It will offer providers an opportunity to agree to specific actions and approaches to supporting children and families with disabilities. Including approaches and a code of behaviour to promote best practice that childcare providers could voluntarily sign up to in full or in parts, would go some way towards promoting accessibility in early years settings.

The project will work closely with the Disability Focus Group of the Dublin Community Forum and will draw on current legislation here in Ireland. It is also hoped to look at international best practice guidelines, and the project will endeavour to represent the issues and concerns as highlighted in the research document.

The Dublin City Childcare Focus Group can be contacted at: 01 2223259 or through the links on dublin.ie, to community forum and then onto the Childcare Focus Group.

Many parents reported a sense of feeling isolated and this was exacerbated by the long waiting lists parents experienced while waiting for a diagnosis.

¹ DESSA promotes the inclusion and participation of people with disabilities in their local communities.



ENSURING THE

Active Involvement & Participation of People with Disabilities and their Families in



ALICE GRIFFIN, Manager, Disability Equality Specialist Support Agency

DESSA, the Disability Equality Specialist Support Agency was established in 2001 to support community organisations in ensuring the active involvement and participation of people with disabilities and their families in local community life. DESSA works from a community development perspective in enhancing the ability of people with disabilities and their families to articulate their needs so that they can influence the processes that structure their everyday lives. DESSA has three broad strategies: capacity building (with both staff of community organisations and people with disabilities); networking; and policy development.



DESSA is a national organisation, funded by the Family Support Agency, the Department of Community, Rural & Gaeltacht Affairs and the Department of Justice, Equality & Law Reform (Enhancing Disability Services Funding) to develop and deliver social inclusion initiatives to people with disabilities and their families. The Childcare Inclusion Programme is one part of DESSA's work programme in 2006/2007.

THE CHILDCARE INCLUSION PROGRAMME

The Childcare Inclusion Programme (CIP) aims to develop a model of good practice for the inclusion of disabled children within community-based and private childcare settings which contributes to the overall mainstreaming of disabled children within their communities. This programme, which will be Dublin-based, will support childcare service providers to take a proactive approach in ensuring the full inclusion and participation of disabled children within their childcare programmes by providing specialised training and supports. The programme will be sustained and mainstreamed through a Training the Trainers Programme which will be an ongoing resource within the region.

The Childcare Inclusion Programme entails the following elements:

- Audit of community childcare provision vis a vis the inclusion of disabled children.
- Inclusive play and policy training programme within an equality framework for childcare staff and childcare management committees.
- Training the trainers programme for childcare staff and childcare management committees.
- Development of a good practice guide in inclusive childcare provision.
- Establishment of an inclusive play network.

A key feature of this project is the development of a working relationship with Playworks UK and Alison John & Associates, British partnership organisations with a vast amount of experience in inclusion in play for disabled children.

The central vision of this project is that disabled children will be able to attend their local childcare service. As a result of the Childcare Inclusion Programme, childcare service providers will have the knowledge, skills and ability to offer an inclusive high quality childcare service to disabled children.

CIP will be delivered in conjunction with the Dublin City Childcare Committee Ltd. and the Dublin Inner City Partnership. The timescale for this project is two years ending in December 2007. CIP is funded by Department of Justice, Equality and Law Reform under the Enhancing Disability Services Programme.

Lets All Play! Seminars

DESSA are running two Inclusive Play seminars in October in the south-east and the north-west in conjunction with local development agencies.

The purpose of the seminars is to highlight the need to make community-based and private childcare and play environments more accessible to children with disabilities and to explore strategies for the greater inclusion of disabled children in community childcare settings.

The seminars will bring together community childcare organisations, play development workers, community development projects, family resource centres, and specialist disability groups to focus on how they can create play space and services that are inclusive for children of all abilities.

The importance of inclusive childcare cannot be overemphasised. The benefits to children with disabilities are far reaching – research has shown that disabled children develop socially and developmentally when along side their typically developing peers. Inclusive childcare promotes diversity – in inclusive settings all children learn about respect for difference, new forms of communication, empathy, friendship and solidarity across difference.

Lets All Play! Seminar – Letterkenny, Co. Donegal, 11th October 2006.
Lets All Play! Seminar – Kilkenny, 26th October 2006.

For further information on any of the above please contact Alice Griffin, DESSA. Tel 01 4163548 or e-mail info@dessa.ie.



It was my 17th Birthday. The family were congregated at the bottom of my parents' bed in true tradition. Mum handed me an envelope and Dad dozily muttered Happy Birthday. Inside was the form for my provisional driving license and 10 driving lessons. I couldn't believe it.

BEING

CAROLINE CASEY Founding CEO, The Aisling Foundation and O² Ability Awards

I was thrilled because I love speed. This combined with my love of travel, movement and freedom makes me the perfect candidate for driving lessons – the “best present in the world”! Since I was young I had loved the idea of driving, whizzing along the roads, fantastic music in my ears and going somewhere, anywhere. I had in fact had a fascination for bikes and the freedom they promised. I really quite fancied myself as a black leather clad biker chick taking to the dusty roads to cruise (this vision was never shared with my father who had conniptions when I looked twice at a Honda 50).

While I was neither the absolute car nor plane enthusiast that my younger sister Hilary was, I still got shivers of excitement when as a child I was in control of anything that moved with an engine – be

that a tractor, motorboat or lawn mower. Now it was time for the real McCoy, it was time to learn how to drive a car, by myself. Nothing could beat this.

On the day of my birthday Hilary and I had the morning off school. We had an appointment with an eye specialist. The fact that both the eye specialist appointment and the day I got driving lessons were on the same day was ironic. More ironic however was that we never considered the contradiction of it all.

The action plan was that after the eye specialist we would head straight down to the police station and deal with my provisional driving license form before heading back to school.



The eye specialist's rooms were just down the road, and as it was a beautiful autumn morning we decided to walk. I remember the clear crisp October light down by Herbert Park, feeling alive and happy. Hilary, Mum and I chatted about a million and one things, mainly cars but certainly not about our appointment. In our minds, it was no big deal. Not for one minute did it occur to either of us as we walked towards his office, especially not me, that anything new would come out of this appointment. Nothing ever did.

We arrived at the specialist's rooms and flicked through the usual out of date Country Living magazines. We had gone past the Enid Blytons that were provided for the kids and Hilary and I far preferred checking out how many houses had swimming pools. Consultant's waiting rooms have a unique atmosphere. It's like you step out of the real world into a vacuum filled with leather seats, overburdened chandeliers, fidgeting hands, expressionless faces avoiding eye contact but full of mutual curiosity, piles of neatly stacked magazines of the strangest variety on over-polished sideboards, flowery carpets, and an imaginary sign that hangs above you stating: "We will have to kill you if you speak". Everyone seems to whisper in waiting rooms!

After a short sojourn in the waiting room, with just enough time to uncover a measly two houses with swimming pools, we were called in.

Once Hilary's examination was complete, I took the chair. When getting my eyes examined I am always very conscious of how my breath smells. The morning of the appointment I spend ages brushing my teeth and mouth washing. I think this is due to the fact that I have such an acute sense of smell myself and one of my pet hates is bad smells. I can't imagine anything worse than the poor consultant having to concentrate on your eyes while dealing with bad morning breath. Hence when being examined I clam my mouth shut and breathe through my nose like a horse, which must look really strange. I still do this now when I get my eyebrows plucked, and I always imagine I look slightly insane.

When being examined by eye specialists they really are very close to you, in fact the only time you are ever really that close to someone is when you are about to kiss them, which is kind of off-putting. On the other hand it is a great opportunity to see things I don't usually see. I very rarely see blemishes of any kind, and when afforded the opportunity for a close up I am often amazed how detailed the face and skin is.

With my mouth firmly shut and nostrils flaring I went through the usual: follow-the-light-around-the-room exercises and the keep-your-eyes-open-until-they-ache while I concentrated on breathing so I wouldn't pass out. Eye specialists are not the chattiest bunch so I was quite surprised when the examination had that sense of conclusion and the Professor remarked:

"I see it's your birthday today, what age are you?"

"17," I replied.

"Doing anything special?" he continued.

A broad smile crept across my face.

"Yip. After this we are going down to the police station to get my provisional driving license before going back to school."

I smiled at him. My excitement was obvious. But something was wrong. He didn't answer. He sort of did that little cough or throat clear. You know the one, the uncomfortable one that people use as a delaying tactic.

"Caroline," he began again with a cough and put his notes on his desk and rolled towards me in his squeaky wheely chair that all eye specialists have.

"Caroline, I don't think that is a good idea."

He was using that voice, the cautious, kind one.

I didn't say anything, just looked at him and thought to myself,

"Why, what on earth is he talking about?"

He then turned to Mum.

"Are the girls unaware that they will not be able to drive?"

"HELLO, UNABLE TO DRIVE. ARE YOU MAD MISTER!"

I sat in my chair, incredulous that this conversation was even happening.

"Why not. Why can't I, I can see, I can see the things you were examining me with, I have glasses." My mouth opened before I had a chance to even process the thoughts.

"Because your sight isn't good enough."

"But when I put my glasses on..."

"Look," he gently pointed to the eye chart. You know the one that is in every doctor's surgery, every optician, every specialist, and apparently every driving school!!!

I looked at the familiar chart. The top letter was clear, and as always was either A or E, even if the specialist had one of those fancy rotating charts that changed the letters.

"This is the level you see to clearly," he pointed to the second line.

"This is where you need to see to at a minimum to drive," he pointed. Where was he pointing? Were there even letters there or was he playing a game. Hilary strained forward on her chair too. I squinted to make my eyes focus better.

As I said, eye specialists are not the chattiest bunch but they also do not say things they don't mean. They choose their words carefully. I knew that. We knew that. You could feel the disappointment seep through the room heavy and low. Not only my disappointment, everyone's.

Mum asked questions, which I didn't hear. I could sense her absolute deflation.



"Will they never be able to drive?" she asked.
"At the moment, no," Professor replied softly.

When we stepped out onto the street, out of the quiet vacuum, we felt flattened. Within that hour my biker dreams were reduced to that of a pillion passenger; Hilary could now only consider bus conductor; or airhostess (in fact not even airhostess as good sight was a requirement of the job), and Mum was in shock.

So many people have asked me, incredulously, how I got to 17 without knowing that I had more than corrective myopia. I do still wonder myself and think what it would have been like, if I had been more aware. And a tiny part of me wishes that it had been different, the part that reminds me how confusing it had been at times.

But the moment I wonder what it would have been like if had been different, is the moment I am so thankful that it wasn't. I would not be where I am now, not have achieved a whisper of what I have, not have dreamed, strived and believed that I could do more. I wouldn't change a thing because I have experienced so many extraordinary things and have lived life so fully that at times I feel I could burst.

I believe there were a complexity of contributing reasons: a decision my parents made; carrying all the hopes, dreams and aspirations of an eldest child and Hilary's sight problem being more obvious.

The decision my parents made, when we were young, needs to be explained. Whereas the others are self explanatory, their decision is what makes the situation quite unique. As any parent, (and forgive me, if I am speaking out of turn as I do not have children) when my parents were faced with the fact that their girls were visually impaired they were devastated, they felt guilty, like they had done something wrong. They were distressed for us, for what it would mean for our future, how would we be like other children? How would we get through life? I am sure when you have children, you want the best for them, you have ideas and expectations for them, and you want them to be successful in life and happy. With an impairment or disability of any kind, those ideals or future may appear a little bit more frightening or certainly less guaranteed. Surely it is hard enough being a parent at all, let alone a parent of a child who has different needs than those you have experienced or relate to. My parents were scared, wanting to fix it, disappointed, and increasingly unsure as we grew up and it became more obvious. I know they wished it had happened to them rather than watch their kids battle or struggle as they went through life.

You also have to remember, Hilary and I were born in the early 70s and so much less was known back then. The information, help and advice available now are incomparable to what was around 30 years ago.

They went through the fear of their children being treated differently, not being able to have a full normal life and so they made a very brave decision. Once they discovered we had usable vision they determined that we would never know that we were different.

Maybe this was as much to protect themselves from the reality as it was to give us the best chance but it was a decision that made me who I am. They decided not treat us like our sight was any different to other kids who wore glasses for as long as they could (in Hilary's case that came far sooner), we would be taught to have the same expectations as any other child, we would be expected to be like any other child and no allowances would be made. By them making that choice, we grew up without the boundaries, limited expectations and over protection of other people who may have impairments.

In my case my "normal" appearance made this so easy, in Hilary's less so due to her very noticeable squint. It is only when I look back at baby photographs of myself that I can see that my eyes were different – they were in a permanent squint due to a sensitivity to light, or I had a patch over half my face.

Looking at those photographs, it occurs to me that I was the goddamn ugliest baby you could ever imagine, with a permanently scrunched-up face. I wouldn't even have passed off as an average looking baby boy and I am amazed they didn't hand me back. When I see the eye patched ones I am instantly reminded of the excruciating pain of plaster removal. Back then the plasters or eye patches were those thick material types with adhesive the strength of bonding glue that ripped off your entire eyebrow when being taken off. And no, whipping it off quickly is no better than slowly peeling it off!

With the exception of trips to eye specialists, acquiring the most hideous pair of glasses at the age of five and the patch thing which stopped around the age of four; (thank God because going around eyebrowless would have been utterly humiliating) I can honestly tell you, my eyes were totally irrelevant to my life.

We were not sent to a special school but a well-known private girl's school where my grandmother had gone. I began Montessori school at three and went through the same as every other child, learning as you went along. I did notice that things were not altogether clear but as I had nothing to compare it to, I knew no different.

I believe there were a complexity of contributing reasons: a decision my parents made; carrying all the hopes, dreams and aspirations of an eldest child and Hilary's sight problem being more obvious.



In class, I was made sit in the front row so that I could see the blackboard. However, after being bullied for being the teacher's pet, I quickly learnt and retreated to the back of the class. In fact I learnt that I saw just as well down the back as the front row desks were not near enough to the blackboard to make out anything much other than a blur.

Gym class often proved difficult, especially when it was time to use the beam or attempt the horse. Hilary and I would often come home bruised from running into the horse rather than jumping over it. As for the beam, we spent our time teetering on the edge of reason not understanding why we were unable to walk the length of it without ending in an awfully uncompromising position and doing damage to our female genitalia.

We were encouraged to try everything, in and out of school.

We were taught how to sail by my father who told us to feel the wind in our faces rather than watch the birdie high up on the sail. We never bumped into rocks because he was always somewhere nearby in a motorboat looking out for them. We played all sports, but never made any teams and just figured that we weren't very good or had bad eye-ball coordination. We were made to play the piano although we strained to see the sheet music, which eventually was enlarged for us, yet I never questioned why. I spent years training in classical ballet copying the girl in front of me. It never occurred to me that every time I got a position or a move wrong that I hadn't been able to see it in the first place. I just assumed I wasn't as good as the others.

Somehow it never occurred to me, and if it did I never thought about it too long, as to why I was so bad at so many things or at least so unobservant and clumsy. I remember one particular time when I was in the finals of an Irish dancing competition, one I had won the previous year and not seeing the edge of the stage, I danced right off it. Another time, as a child I remember cycling down someone's drive and not seeing that the gates were shut. I had the imprint of the gate on my face for three days! Classy bird!

Going through puberty at the best of times is no easy journey for anyone, with or without sight problems and for every mortifying situation I found myself in, my friends had others. I was no different. Summits on boys, clothes, hideous school, unfair parents were held in Nicola and Sinead's bedrooms where we over analysed, preened, dealt with endless mini dramas and pretended to do homework. Both girls were invaluable when it came to helping me decide what to wear as I was unable to clearly judge for myself in the mirror. But I did the same in return. What are girlfriends for? I always asked

their opinions about a guy if he approached me at a disco for a dance, but isn't that what all girls do? After taking one too many risks on accepting a dance with a guy who looked decent on the approach and who I discovered, when I could eventually see him, (when all was too late and he had his tongue down my mouth) he resembled Adrian Mole, it was mandatory to get girl input into dance partner selection.

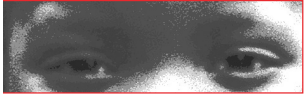
Going through puberty at the best of times is no easy journey for anyone, with or without sight problems and for every mortifying situation I found myself in, my friends had others. I was no different.

Being so awkward at many things certainly made me unsure of myself. Not clearly seeing doorways, book covers, people's faces, posters, bus numbers, toilets without any obvious explanation made you often feel stupid, slow, and clumsy. But being a teenager is about that. Part of growing up is feeling like a turkey amongst swans.

The thing is, there were always explanations. In the absence of the real reason, which I was totally unaware of, my reasons seemed fine. Hilary and I managed, because we had to. Our parents made us believe that we were no different, especially me. If I wanted something, I could get it if I worked for it. They never once told me that my sight was not good enough to do something, they never tried to over-protect me – well except for going out at night – and that is the prerogative of any parent.

While Hilary had to face some reality at a younger age they never hinted at me that there might be problems down the road, so I never saw or expected them. By making me believe that I was no different in any way I believed that like any other sighted child I could do most normal things. As they never instilled limitations in my mind I never saw them.

To me that is the lesson, the only limitations we have are those we put on ourselves.



THE EXPERIENCE OF

DISABILITY

— a parent's perspective



“Just take her home. She’ll never amount to much, but she shouldn’t cause you too much trouble either.”

They were the two sentences that defined us. Not immediately, but over time they turned my wife, Frieda, and me into often reluctant, usually frustrated, and frequently very angry members of the disability movement.

We don't have a disability, either of us. At least I don't think so. But we have frequently been spoken to by experts in words of one syllable. We've sat in front of them with that sinking feeling, the realisation that this person thinks we're not the full shilling. We've been patronised by politicians, had all sorts of assumptions made about our backgrounds (particularly the assumption, which has only sometimes been true, that we are 'socio-economically deprived'), told that we had been given a special gift, and promised the sun, moon and stars by every Government Minister we've ever met.

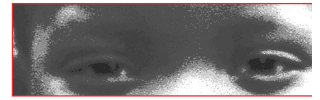
What we do have is a daughter with a disability. Mandy, to be precise. Now 31 years of age. And her disability is Down's Syndrome. It's an incurable condition, but that didn't stop the system calling her for an annual check-up in case we had found the cure and were keeping it to ourselves.

Whatever name we apply now, I didn't know what to call it when Mandy was born. In 1972, in the middle of the summer, Frieda had gone into hospital for our first baby, not knowing anything of what was to happen. I went too, but was told I would be hanging around for hours, as a first labour can last for ever. So I left the hospital, leaving the number of a friend's house so I could be called when things started in earnest.

Things started in earnest almost as soon as I left. Frieda was told that the baby was very distressed – no reason given – and an immediate Caesarean section would be essential. She was whipped up to the theatre, on her own, and anaesthetised.

Whoever was minding the phone number I had given them forgot it. And Mandy was born with her father missing and her mother all alone and very groggy.

Maybe that was why they decided not to tell anyone that night. When I arrived, as Frieda was coming out of the anaesthetic, everything seemed all right. They knew immediately, of course, in



the hospital. All we saw was a beautiful, delicate, porcelain doll. We didn't know the tell-tale signs they know – the floppy muscles, the flattened nose, and the fact that Down's Syndrome babies, strangely enough, have only one life-line right across the palms of their hands.

Anyway, they told me the following day. A nurse was either deputed to do the job or took it on herself.

"Mr Finlay, I'm sorry to have to tell you that your daughter has Down's Syndrome."

"Oh right. Is that serious?"

"Well – do you know what Down's Syndrome is?"

"No, I'm afraid I never heard of it."

"Well, have you ever heard of mongolism?"

And then I knew. But I still knew nothing. A doctor would be able to explain it to me. But it was Sunday, and he was terribly busy (as they always are on a Sunday, apparently). I would have to make some sort of fist of telling Frieda myself. Nowadays, Frieda often talks to experts – at least, when they are being formed, as students, she and some other parents try to get through to them that these are all issues that affect people. They do it by telling their own stories, and this is how Frieda has described her own reaction to the news of Mandy's condition in one of the talks she has written:

"During my first pregnancy, I had dreams about my wonderful child, and all that he or she would do and be. I had an emergency Caesarean section, so I was told Mandy had Down's Syndrome before I saw her.

All I could imagine through my shock was a wizened, shuffling, snotty-nosed, young, old-looking adult. My life was shattered; my rejection was instant; I was scared of my monster baby. Of course, I had never seen a baby with Down's Syndrome.

When I saw her, she looked quite beautiful, like a little doll. But that was no consolation. I felt imperfect, and not a proper woman. I wanted to hide her. There was something wrong with me – what would people think – after all, if I had all these attitudes about people with a mental handicap, weren't people going to have the same attitude about me and my child?"

Some did have attitudes, of course. Not the doctor we eventually got to see. He couldn't have been more casual, more laid-back, more brutal.

"Just take her home. She'll never amount to much, but she shouldn't cause you too much trouble either."

Over the years, though, Mandy caused a lot of trouble. Bits of pain too. Here's Frieda's account again:

"I can also remember when she was a toddler, the first time we took her for a walk up Killiney Hill. I think every bouncing healthy child in Dublin, from 1 to 12, was out there that day. And it hurt. Again it brought home the reality of my situation. You live coming to terms with it every second day.

Don't ever think that parents get used to having a child with a disability. We don't. We develop enough scar tissue to stop us bleeding in public, and to carry on some kind of normal life.

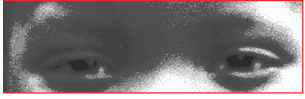
Even though I have been campaigning for many years for her rights, and shouting about the importance of equality, it was only recently I realised how equal my daughter really is. It is very important to understand how we perceived our child who has a disability."

Unconsciously, we blamed her for her disability. We blamed her for the fact that other kids were making better progress, were walking and talking before Mandy. We blamed her for the pity we seemed to attract, and even, as she got older, for the fact that her identity in some ways was stronger than ours. We were the parents of the Down's Syndrome girl.

As time went by, however, we discovered we weren't alone. We weren't alone in a number of ways – society as a whole, for instance, holds people with a disability responsible for their shortcomings. That's why we went through a period when all our kids with a disability needed to be 'normalised'. Later, when society came to realise that normalisation mightn't be too easy, our kids needed to be "integrated".

"I'll tell you about integration," I heard a mother say at a meeting one night. "My son has a job in the local supermarket – he's integrated with the other boys. At lunchtime they play soccer in the yard, you can see them any day. The boy on his own, with no-one talking to him, sitting on the steps watching the others play ball – that's my integrated son."

The buzz-words were only part of the stupidity, only part of the way in which people with disabilities are at fault. The annual check-ups to be sure we hadn't invented a cure. The fact that when Mandy was in a school with brighter kids she couldn't speak as well as them – and so she got priority for speech therapy. When she was in a school with kids of her own ability they all spoke the same – so none of them got speech therapy. The fact that your role as parents was to take a tin cup once a year and stand outside the church, so people could go out of their way to make themselves feel better by giving you their small change. And you'd stand there mumbling thank you while your daughter was receiving charity.



“My son has a job in the local supermarket – he’s integrated with the other boys. At lunchtime they play soccer in the yard, you can see them any day. The boy on his own, with no-one talking to him, sitting on the steps watching the others play ball – that’s my integrated son.”

Later, sexuality became an issue. You can see sexuality flourish in every teenager – but it happens with a layer of religion, attitudes, education, and discrimination. Mandy had none of these – that’s what made the sexuality so frightening. When she reached thirteen years of age, and started to develop physically into a young woman, we weren’t ready. She wasn’t ready – her mental ability ranged between five and ten years of age at the time. Why should she be getting the body of an adult? Around that time she went through a phase where she would follow anyone wearing trousers whether he was a family friend or stranger, or almost sit on top of any man, young or old, who came to the house.

What you do come to realise, perhaps over more years than it should take, is that disability isn’t an issue of fault. At least if it is, the fault doesn’t lie with the person with a disability. Disability is a barrier, or a series of them, and those barriers are erected by all of us. Frieda began dealing with those barriers by finding other parents and working with them. They’ve spent a lot of time together, plotting and planning and making life difficult for the establishment. And all the time determined to do what they can to tear those barriers down. I got involved through politics, trying (and usually failing) to persuade people that disability is the last great civil rights issue.

Until we got involved in Special Olympics, we believed there was no limit to human potential. But we also thought it was a kind of cliché. Special Olympics taught us it was true.

In the last century, all the great stories were of people overcoming. Women overcoming the barriers to equality, from the struggle to be allowed to vote right through to the liberation movement. The struggle for civil rights in black America, and the inspirational leadership

of people like Martin Luther King. (The theme song of the movement – “We shall overcome”.) The even harsher struggle for freedom in South Africa, and the monumental and historic role of Nelson Mandela. And the fall of the Berlin Wall, typifying for many of us the final collapse of some of the most cruel barriers to freedom.

But at every Special Olympics event, you can see people overcoming. You can see grace and dignity in the face of adversity. You can see people aiming for a genuine and clean sporting ideal. And you can’t fail to be drawn into that, almost against your will.

It happened to us the first time we went to an international sporting event. (We had been at local competitions in Dunmore House, where we knew all the competitors and spent all day cheering them on. But you always do that when it’s your own local club, don’t you?)

The international event we went to was the World Summer Games in 1995, in New Haven, Connecticut. The reason we went was Mandy who was picked on the Irish basketball team for the Games. (Remember the doctor saying “She’ll never amount to much ...”) Mandy was twenty two when she became the first member of her family to represent her country abroad, and to wear the green blazer with pride.

The week of the 1995 Special Olympics was a revelation. I can still remember thinking how corny it was when I heard the athlete’s oath for the first time – “Let me win. But if I cannot win, let me be brave in the attempt.” The following week taught me that it might be corny. But when the athletes say it, they mean it. And they are as brave as anything you will ever see.

In the middle of that week, we went to the athletics, to see how the Irish team were doing. They were doing well, and went on to win quite a few medals in track and field. But it was one of the heats in the 1500 metres that I will never forget.

They were lining up for the event as we took our seats. In the outside lane, so close to us I could see his eyes, was a black athlete. The eyes were dull, slightly unfocused. And he had only one leg – he was using an old-fashioned wooden crutch.

He was slower than all the rest to start, and by the end of the first lap it was clear that he was in trouble, without the remotest chance of qualifying for the next round. By the time seven of the eight competitors had finished the heat, he still had more than a lap to go. And he was hobbling badly.

But he never stopped. More than that, he never faltered. Although from where we sat it looked as if each step was more painful for him than the previous one, he was determined to finish.



And little by little it became clear that the entire crowd was determined to help. As he eventually crossed the line, collapsing into the arms of his coach, two and a half thousand people gave him a standing ovation. None of them, I'll bet, could remember who had won the heat. And none of them will ever forget the way that African athlete overcame that day.

That World Games in 1995 taught those of us who were there something else as well – anything Connecticut could do, we could do better. The idea of bringing the Games to Ireland started in New Haven, and it was Irish families that began the movement that culminated in 2003 in the never-to-be forgotten Special Olympics World Summer Games in Dublin, bringing 7,000 athletes and their families to Ireland.

But most of all, that week in Connecticut showed us that courage and grace are no clichés. They are more alive in the Special Olympics movement than almost anywhere else. The South African song about apartheid – “the higher you build your barriers, the faster I will run” – might have been written for our athletes.

But we're still building the barriers. We're still expecting people with disabilities to overcome every day, without the sort of backup we take for granted. Isn't it just as well they have grit and determination, even if we can't see it?

Mandy is a woman now, and she lives independently about half the time, with a number of her friends in a community that is protected. She didn't get there as a right, in fact she has no rights. There is no law that says we should all take some responsibility for the barriers that are put in the way of people with disabilities.

Of course, we have a Disability Act now. It gives people with intellectual and other disabilities the right to an assessment. There are rights of enquiry, appeal, and complaint in the Act. But there's no right to any of the services suggested by the assessment, and the entire legislation is riddled with 'get-out' clauses that turn the process into a huge bureaucratic maze that people with a disability have to work their way through to get any services at all.

The higher level of awareness that resulted from parents' anger and action, and perhaps also from the success of the World Games, has resulted in more funding for a Disability Strategy, and a requirement that Government Departments publish sectoral plans to promote the inclusion of people with a disability. We'll see in due course whether that makes a difference in the absence of any real legislative rights.

What we know is the potential that people like Mandy have. What we want to see is the political will to enable them to unlock that potential. That's why parents argue for rights. And we will go on arguing until they finally have the rights the rest of us take for granted.

But at every Special Olympics event, you can see people overcoming. You can see grace and dignity in the face of adversity. You can see people aiming for a genuine and clean sporting ideal. And you can't fail to be drawn into that, almost against your will.



Useful Resources on Special Needs

The following resources are available from the NCRC:

ADHD: The Facts

Oxford University Press, 2004

Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage and Meltdowns

Autism Asperger Publishing Co., 2005

Being in a Wheelchair

Chrysalis Children's Books, 2004

Brothers and Sisters of Disabled Children

Jessica Kingsley Publishers, 2004

Children with Additional Needs in Early Childhood Services

IPPA The Early Childhood Organisation, 2004

Disabled Parents and Their Children: Building a Better Future – A Discussion Document

Barnardo's, 2005

Developing an Advocacy Service for People with Disabilities (Volume I)

Goodbody Economic Consultants, 2004

Identifying Additional Learning Needs: Listening to the Children

RoutledgeFalmer, 2005

Inclusion in Pre-School Settings: Support for Children with Special Needs and Their Families

Pre-School Learning Alliance, 2004

Listening to Young Disabled Children

National Children's Bureau, 2004

Learning and Learning Difficulties: A Handbook for Teachers

David Fulton Publishers, 2004

Pre-Schoolers with Autism: An Education and Skills Training Programme for Parents

Jessica Kingsley Publishers, 2005

Relate: Developments in Disability Policy and Services

Comhairle, 2004

Social Skills Training for Adolescents with General Moderate Learning Difficulties

Jessica Kingsley Publishers, 2004

Special Brothers and Sisters: Stories and Tips for Siblings of Children with a Disability or Serious Illness

Jessica Kingsley Publishers, 2005

Special Needs and Early Years: A Practitioner's Guide

Paul Chapman Publishing, 2003

Stepping Out: Using Games and Activities to Help Your Child with Special Needs

Jessica Kingsley Publishers, 2004

Tics and Tourette Syndrome: A Handbook for Parents and Professionals

Jessica Kingsley Publishers, 2004

Transfer Boy: Perspectives on Asperger Syndrome

Jessica Kingsley Publishers, 2005